

## 'I don't feel like a gender, I feel like myself':

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## **MANUSCRIPT**

**‘I don’t feel like a gender, I feel like myself’: Autistic individuals raised as girls exploring gender identity**

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## **Authorship confirmation statement**

This article is based on the original Masters research of Marianthi Kourti, who was responsible for the research design, data collection and analysis. As first author she was responsible for leading the initial conceptualisation and drafting of the paper, plus subsequent conceptual development and editing.

Andrea MacLeod supervised the research and contributed to the research design and analysis. She helped to conceptualise the paper, wrote some elements and contributed to its conceptual development and editing.

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## **ABSTRACT**

**Background:** This paper addresses a gap in current research by considering perceptions of gender within autistic adults raised as girls.

**Method:** We report on an online focus group, in which twenty-one individuals who had been raised as girls discussed their gender identities. This discussion was part of a larger study, involving forty-three participants from eight countries. An emancipatory approach was employed, so that participants set their own agenda, thereby highlighting directly that gender identity was significant for them. The discussion was open for two weeks, following which the transcript was analysed using Applied Thematic Analysis.

**Results:** Participants reported not identifying with typical presentations of the female gender for a variety of reasons, linked both to autism and to socio-cultural expectations. Participants described childhoods of being a tomboy or wanting to be a boy, having difficulties conforming to gender-based social expectations and powerful identifications with their personal interests.

**Conclusions:** Consideration is given to the ways in which autistic individuals conform to, or resist, gendered roles, as well as the implications for identity formation within autistic individuals raised as girls. The innovative emancipatory design proved effective in giving voice to a group who have had little presence within the academic and medical communities and, through its use of online platforms, in engaging a large and internationally-based participant sample. This paper highlights both the importance of approaching autism from an intersectional perspective that takes greater account of context, and the unique contributions that autistic individuals can make to current understandings within autism research.

## **Introduction**

Investment in research focusing on the autism spectrum has risen rapidly over the past two decades. However, the vast majority concentrates on early childhood<sup>1,2</sup>. The need for more research that directly addresses the needs of autistic adults and explores their lived experience has been well identified<sup>3,4</sup>. The existing research base also tends to focus upon males, so that support systems are therefore tailored towards the needs of males, despite growing evidence that the female experience is significantly different and in need of particular attention<sup>5,6</sup>. The limited literature available suggests that autistic individuals, including autistic women, may be at higher risk of serious mental health issues and suicide<sup>7,8</sup> and overall premature mortality rates<sup>8,9</sup>. Additionally, there is considerable evidence that within sexual minority and/or transgender groups, there is a higher incidence of suicidal behaviours<sup>10,11</sup>. Thus, for autistic individuals experiencing atypical gender identity, there is a complex interplay of different and distinct challenges that may be compromising their mental health, but which have been largely overlooked. This paper seeks to address this gap in our understanding, by reporting on a study which explored the lived experience of adults who were raised as girls and diagnosed with autism in adulthood, using an online methodology to engage them as active participants at all stages of the research. Within this paper we refer to our participants as adults raised as girls, in recognition of the diversity of gender identity represented here.

### ***Gender expression and autistic individuals***

The social presentation of the self can be a particular struggle for disabled individuals<sup>12</sup>. For women, it has been noted that being disabled (particularly physically) can make it very difficult to identify with the desirable female image presented by the media<sup>13</sup>. Autistic women may face similar, but also very different, kinds of struggle. Autism is often described

as an ‘invisible’ disability and has its own unique personal and social challenges<sup>14</sup>. As Shelly (2004, 7)<sup>15</sup> has observed:

*“If gender is a social construct, then autistic people, who are less aware of social norms, are less likely to develop a typical gender identity. Autistic girls may not envisage themselves becoming wives and mothers when they grow up. If social constructs are made of symbols and representations, then autistic concreteness may lead to a less generalized, and more personal gender identity. Therefore, autism may redefine womanhood in a unique way.”*

Autistic gender is being discussed at length within autistic communities, which often describe atypical presentations of gender<sup>16</sup>, whereas when discussed in academia, autistic gender expression is often pathologized and framed in traditional binary terms (masculine/feminine)<sup>17</sup>. The challenges autistic individuals face consist of a combination of a complex interplay between different aspects of their personal lives and identities<sup>18</sup>. It is imperative, therefore, to investigate them in a meaningful way that takes this into account.

### ***Emancipatory research***

This project endeavoured to follow the main principles of emancipatory research, an approach akin to participatory research, whereby participants are active stakeholders within all aspects of the research process<sup>19</sup>. Throughout this study, participants were encouraged to be co-researchers, directing the research agenda, setting their own questions and commenting upon the analysis and findings. In this way, it was hoped that they would derive personal benefit from the research. We aimed not only to record and represent their experiences, but also through dissemination to initiate broader change for the benefit of the whole community<sup>20</sup>. Emancipatory research has only recently and very sporadically been used in the field of autism research<sup>21 22</sup>. The social and communication difficulties associated with autistic individuals have caused researchers to be cautious, perhaps overly so, about consulting them, despite evidence from autistic and non-autistic researchers that this can be



done effectively<sup>23,24</sup>. This relative absence of representation of autistic individuals deprives the research community of the insights of autistic people, and as Ne’eman has observed, has put autism behind other areas of disability self-advocacy<sup>25</sup>.

There are important benefits for research communities and participants alike in adopting an emancipatory research approach. Waltz<sup>26</sup> has claimed that the accuracy of results is likely to improve by directly involving participants, because their insights can provide important information about their needs, priorities and challenges, which may be overlooked by non-disabled researchers. Likewise, autistic researcher Milton<sup>27</sup> has reflected on the production of knowledge in autism studies and the fact that it is largely based on interpretations from non-autistic researchers, neglecting the autistic perspective. Yet the insights of autistic participants are of the utmost importance, if research communities are to have access to their unique ways of thinking<sup>28</sup> and reflect their priorities. An emancipatory approach was also deemed appropriate since this research was inspired by the personal experiences of the first author, who is autistic. The first author met most of the participants online, through her journey to awareness of her own challenges.

## **Methods**

### ***Participants***

The entire study recruited forty-three participants who were raised as girls from eight different countries (UK, USA, Canada, Norway, Germany, the Republic of South Africa, Australia and New Zealand) (of which twenty-one participated specifically in the discussion on gender identity that is the focus of this paper). Ages ranged between twenty-one and fifty-two. The first researcher originally made a post on a Facebook group for autistic women which was dedicated to connecting autistic women with each other and discussing issues that are faced by them. The sample was self-selected and, using a snowball approach, participants could refer other appropriate contacts to the first author to be included in the research

process.<sup>29</sup> In the post made in that Facebook group participants were asked if they would be interested in participating in a research study exploring the experiences of autistic women that would be conducted by the first author as part of her M.Ed. dissertation. Participants were asked to join a new, ‘secret’<sup>1</sup> group in order to participate in the research. In order to fulfil inclusion criteria, participants had to have been raised as a girl, be over the age of eighteen, willing to participate online via Facebook, and self-identify as being autistic.

### ***Approach***

This research was conducted entirely online. Online research allows the application of different methodological approaches<sup>30</sup> and can facilitate the anonymity and protection of the participants<sup>31</sup>. In a study that included women of a sensitive population - surviving birth trauma<sup>32</sup>, online interviews were found to make participants feel heard and acknowledged, creating a sense of belonging through their connection with other women experiencing similar challenges and providing closure on some aspects of their past. It can provide access to populations not otherwise accessible<sup>31</sup>, which was important in this case, where the target group are otherwise largely ‘hidden’ and often isolated. Indeed, it enabled access to a multi-cultural, international and diverse sample. It was also deemed appropriate as electronic communication is often cited by autistic adults as a preferred way to communicate<sup>33,34</sup>, due to its relative simplicity and lack of social pressure. The study received formal ethical consent from the University where it was conducted. However, in keeping with its emancipatory philosophy, the negotiation of consent was treated as an ongoing consensual process rather than one event. Through the dialogues both during and following the data collection and analysis, participants had multiple opportunities to raise questions or concerns.

### ***Data collection***

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<sup>1</sup> A ‘secret’ Facebook group is one that cannot be accessed or searched by anyone other than its members ([https://www.facebook.com/help/220336891328465?helpref=about\\_content](https://www.facebook.com/help/220336891328465?helpref=about_content)).

Data was collected via an online focus group discussion. The intention was to create an online environment similar to those where discussions of this type were already taking place (ie. online groups for autistic adults), in order to encourage a naturalistic discussion to evolve inside this protected space. Table 1 illustrates how the data collection and analysis for the study as a whole was planned, in order to subvert the typical structure, whereby the researcher drives the research agenda and participants respond. Instead, the first author sought to position herself as enabler, with participants driving the agenda. [Insert Table 1 here] After formally consenting to participate in the research, participants were invited to join an initial discussion ('stage 1') in which they were simply asked to describe the topics they would like to discuss during the research. Contributions were then analysed and themed into five separate discussion topics ('stage 2') In this way, discussion topics were decided upon by participants, rather than the first author. Each discussion was open for two weeks in turn and the entire process of data collection (for the whole study) lasted approximately three months. After the end of the research process, the participants had the opportunity to provide comments on the final draft of the dissertation ('stage 3'). In this paper we have focused only on the second discussion topic, which centred on personal identity (see Appendix 1).

### ***Participation***

The discussion developed freely over the agreed time period, deliberately following a relatively unstructured approach in order to prioritise the voice of the participants rather than the curiosity of the researcher<sup>35</sup>. The first author took an observing role and did not participate in the discussions, other than to post the initial topic to open the discussion and to send reminders before it closed. No comments were made, and no clarification was sought. The intention throughout was to uphold emancipatory principles and not influence participants' contributions, consciously or unconsciously.

Participants could contribute in two ways: either by posting comments or by 'liking' specific comments posted by others. Comments which had been 'liked' were considered separately during the analysis as it seemed likely that some participants might prefer to 'like' comments with which they agreed, rather than make a comment directly, and the 'liking' of a comment was a reasonable indicator of support or agreement for the content. In practice, most participants chose to participate in both ways. Individuals within the group were identifiable by their comments, so participants were also given the option of sending a personal message or e-mail to be posted anonymously by the researcher. One participant took this option on one occasion.

Following analysis of the discussion data, the analysis itself was posted in the group area so that participants could read and comment ('stage 3'). Feedback was unanimously positive, and participants liked the clear and systematic presentation of the final product:

*"The main thing I noticed is how amazing is that you managed to get together all those statistics on how many people liked and commented and stayed silent in each thread, that just baffles my brain!" (Ruth).*

After the research project ended, the group continued because participants wanted to stay in touch and be informed about the progress of the project. The final draft of this publication was also shared in the same group. Participants agreed with the content and also noted their appreciation that something was coming from the project in which they had participated.

The data was analysed using Applied Thematic Analysis (ATA), a phenomenological approach which focuses on representing participants' experiences and perceptions, as well as be systematic and transparent in its methods<sup>36</sup>. NVivo 2010 was used for the coding process, which followed a close reading of the transcript. Data were coded freely in the first instance, before being grouped into themes according to frequency. Likes were considered separately rather than as part of core data, since these were open to misinterpretation. (Sometimes it

was not clear which part of the post the ‘like’ referred to, and sometimes was used as a means of showing support rather than necessarily agreement). Analysis was conducted primarily by the first author, with input from the study participants and the second author.

## **Results**

During this two-week discussion, twenty-one participants participated overall. Nineteen participants posted comments, of which fourteen also ‘liked’ other posts, and two ‘liked’ other posts without commenting themselves. All the names included in this document are pseudonyms created to preserve the participants’ anonymity.

Table 2 summarises themes and participation relating to this discussion [insert table here]. These themes will now be considered in detail in two respects: firstly, in terms of how participants described expressing their gender as they were growing up, and secondly, the ways in which participants perceived their gender identity in relation to their experience of being autistic.

### ***Gender expression and gender identity***

Notably, all participants in this discussion felt that they didn’t relate to the typical presentation and activities of the female gender. The majority reported having male interests or being ‘tomboys’: *I grew up a tomboy...I played on a boy’s baseball team for years, had mostly male friends, and as an adult have mostly held ‘male’ jobs, landscaping and construction. However, I have a more compassionate, ‘feminine’ temperament, and enjoy quiet activities like sewing and drawing (Liz).*

or wanting to be boys growing up:

*I believed myself to be a boy and was mortified and sick when I start developing as a girl (Ruth).*

A number of participants described occasionally enjoying activities that they considered to be typically female *as well as* activities they considered to be typically male:

*I always had a pretty even split of "girl toys" and "boy toys" - baby dolls, Ninja Turtles, stuffed animals, Ghostbusters, stickers, dinosaurs, crafty stuff, Lego. (Kate).*

Most participants reported having a fluid sense of gender, being gender-queer or feeling male and female and seeing others in the same way. For example, Clare described:

*Love & desire have more to do with the personality of the individual than gender does.*

An absence of a sense of gender, or being unsure of how their gender should ‘feel’ was another common report:

*As a child and even now, I don't 'feel' like a gender, I feel like myself and for the most part I am constantly trying to figure out what that means for me (Betty).*

Many participants also described feeling agender or not identifying with a gender:

*I don't feel like a particular gender I'm not even sure what a gender should feel like (Helen).*

Only one participant reported themselves as being transgender:

*I remember the first time I read about gender dysphoria in a psychology book I understood myself and gender. I am a man in a female body, [...] I have been a boy who has grown into a strong, gentle man (Mike).*

Participants also noted that some of their experiences reflected prevalent attitudes when they were children. As Sally reflected:

*Sometimes I wish I was born during today's times. Today is a different age, and so many differences are being accepted and embraced. Maybe there's much more hope in the future if things keep going that way.*

Participants also described ‘masking’ their autistic behaviours during childhood but tended to view this as something they resisted as adults. *(I am even less likely to conform to anything now that I'm older. Rachel)*

These accounts, though very different, conveyed a common experience of individuals finding themselves unable to identify with the typical gender expectations within their environments, and their individual struggles to make sense of themselves against these.

### ***The effect of being autistic on gender identity***

Participants also discussed how discovering their autistic identity has helped them accepting themselves. Sally said:

*“Finding out that I am an individual with autism has helped me understand myself a lot. It explains why I've been so different and why I struggle with male/female roles and identity. It helps me to better accept myself. It doesn't solve the struggles, but it helps with my own personal acceptance.”*

Of particular note is the extent to which interests played a role in defining both gender identity and identity in general. Most participants within this study characterised their sense of identity as ‘fluid’ and defined more from their interests: *“My sense of identity is fluid, just as my sense of gender is fluid [...] The only constant identity that runs through my life as a thread is ‘dancer’. This is more important to me than gender, name or any other identifying features... even more important than mother. I wouldn't admit that in the NT world as when I have, I have been corrected (after all Mother is supposed to be my primary identification, right?!) but I feel that I can admit that here” (Taylor).*

*Mine is Artist. Thank you, Taylor. (Jessie)*

Participants also discussed ways in which the discovery of their autistic identity had helped them to accept themselves. Sally wrote: *I don't want to be male. Yet I don't share the female interests most women have. I don't fit either. I wish there was a neutral. (Sally)*

Here, participants spoke passionately about areas of identification related to personal interests. Autism in this context served as an explanation for their personal outlooks,

perceived to be at odds with typical non-autistic perspectives. These were accounts of more fluid identity constructions, less constrained by social expectations.

## **Discussion**

To date, autism research has been largely male-focused, understood to be a predominantly male condition. This has greatly and detrimentally affected the experiences of autistic women<sup>37</sup>, and indeed any autistic individuals not conforming to the expected ‘type’, such as queer<sup>2</sup> autistic people<sup>38</sup>. Many have grown up not knowing they are autistic or have been repeatedly misdiagnosed. Within this study, we have endeavoured to tackle existing gaps in the research by engaging directly with autistic adults who have been raised as girls.

Participants in this study provided powerful narratives describing feelings of alienation provoked by the pressure to conform to ‘gender-typical’ and ‘neurotypical’ expectations of them. Gender identity is traditionally perceived in terms of binary categories, which is not useful for those who do not conform to them<sup>39</sup>. Recently, discourses on gender have included a wider range of gender identities which reflect more accurately the diversity of human experience, for example agender, bigender and transgender<sup>40</sup>. Whilst mainstream acceptance of this diversity may still be problematic, there is at least a growing recognition of its existence. At the same time, societal expectations of women within western cultures have gradually begun to allow a broader range of opportunities and interests.

Autistic individuals have described feeling pressure to “mask” their autism.<sup>14,41,42</sup>. They often do that by ‘performing’ normative gender roles. In doing so, they are often adopting behaviours that are not instinctive to them and pretending to be someone they are not. For the participants of this project, this attempt to conform stopped as they grew older, but was a

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<sup>2</sup> ‘Queer’ is an umbrella term that is used to describe people who are not heterosexual and/or cisgender (do not identify with the gender they were assigned at birth).



practice many of them adopted at a younger age and may have been part of the reason they were confused about their gender identity. This may also provide some explanation for the high occurrence of mental health problems in autistic individuals. Participants in this study articulated these challenges and their own efforts to navigate them, describing struggles that persisted over many years. Davidson and Tamas <sup>16</sup> highlight that ‘doing’ gender as socially expected can be incredibly draining for autistic individuals. Discovering their autistic identity might help autistic individuals process their gender identity as well. Autism is directly associated with difficulties in understanding social concepts and social rules. Much has been written about the tendency, deliberate or accidental, of autistic people to breach social conventions.

There were also positive narratives describing ‘growing out’ of the pressure to conform, and participants gave passionate accounts of the ways in which they identified with, and were supported by, the interests they chose to follow personally or professionally. The connection between participants’ interests and gender identity was an important and unexpected finding of this research. Participants’ questioning of their gender identity often stemmed from their interests not conforming to those typically associated with femininity. According to Butler <sup>43</sup>: *“the body becomes its gender through a series of acts which are renewed, revised, and consolidated through time”*. In other words, participants found it difficult to see themselves as women because their acts, motivated by their interests, differed significantly from those of the majority of other women. Autistic individuals have been described as being monotropic in their pursuance of personal interests <sup>44,45</sup>, which in turn can become a very important part of their identity. This is perhaps why being identified as autistic was described by the participants as helpful in understanding their difference. To return to Shelly’s <sup>15</sup> quote: *“Autism may redefine womanhood in a unique way”*.

These findings have important implications for the sector, both for our understandings of autistic individuals and for our understandings of the barriers they face. On the one hand, the accounts here give an indication that gender identity is a significant issue for many autistic individuals as they grow up. Given the vulnerability to mental health difficulties and social exclusion for both autistic individuals and for individuals with non-binary gender identities, we suggest that services within both sectors need to recognise this intersection. On the other hand, these accounts reinforce the importance of supporting and recognising the personal interests of autistic individuals. Here, personal interests served not only as enjoyable pursuits and a potential means of success within employment. They also provided positive and consistent identities for the participants in this study, serving as an important anchoring point for them in their lives. Studies which have explored intersections between different marginalised identities have considered how the interplay between social identities might serve to shape a new, unique sense of identity not represented in the current discourses. The accounts in this study are significant in illustrating the ways in which autistic individuals both navigate and move beyond the constraints of their conferred identities (autistic/non-autistic; female/non-binary) to inhabit new identities of their own making<sup>46-48</sup>.

Its findings also serve to provide an important reminder – autism does not exist in a vacuum - as a social disability, it is by definition socially situated. Attempts to understand the full range of autistic experiences need therefore to take account of the complex interplay of different factors within the individual, whether they relate to gender, race, culture, class or anything else likely to influence personal identity<sup>49</sup>. This research, in focusing upon two elements, could not avoid the neglect of others, but nevertheless has striven to provide a platform for some of the more marginalised autistic voices. More autistic-led, participatory and emancipatory research is needed in order to increase our understanding of how best to break

down the barriers that constrain opportunities for autistic individuals and to understand autism not as a biological deficit, but as a form of “neurological queerness”<sup>50</sup>.

Within this study, we have endeavoured to tackle existing gaps in the research by engaging directly with autistic adults using an emancipatory framework. However, every study contains limitations, and we recognise those inherent in the methods employed here. Our research participants were self-selected and by necessity had literacy skills and an interest in online communication. Generalisability of findings may therefore be limited. Nevertheless, the research represents the voices of a group who have often found themselves misrepresented and/or completely absent from academic discussions, and so, despite the limitations, it provides important new understandings and may well have broader relevance.

The data for this study were collected by the first author, endeavouring to the principles of emancipatory research throughout. The initial conception of the project was influenced by the community from which the participants were recruited, and the first author was a part of the autism community before the beginning of the process. This was an important factor behind their motivation to participate and share sensitive areas of their lives, as many of them confirmed at various times. Although the first author’s personal gains from the process are undeniable, there is evidence that participants did perceive a personal benefit, as many of them disclosed to the first author that participation had been valuable for them. Participants commented that the study was an accurate and valuable representation of their voice and were enthusiastic to have its findings published. They also reported that participating in this project helped them communicate their experiences more easily to others outside of the study. Perhaps the most important message arising from the emancipatory approach is the freedom of expression it offered to its participants. Through this, notwithstanding the points above, participants not only reflected upon these aspects of their identities, but also highlighted the need to go beyond them and see the ‘dancer’ and the ‘artist’. Just as autism research risks

neglecting the experiences of autistic women, research such as this study, with its focus on ‘identities of disadvantage’ potentially risks neglecting the individual experience. Our participants ensured that this did not happen, and instead offered empowering accounts of the development and expression of their different identities, negative and positive.

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## APPENDIX

### Appendix 1:

The discussions of this project were introduced as follows:

Hello all! ☺ This is the discussion timetable! I will post it here and you can also find it in the attachment below! I will send this post as a link to everyone in the group, so that everybody is aware of the fact that we are starting! I will also start doing weekly alerts from next week, to remind you all of the subject we are talking about each week! So, without further ado, this is the timetable!

21st March - 4th April: "Special interests and school experiences"

(comments leading up to that were: ""Power of special interests. I was such a geek at school, but it really helped when I was being bullied and such like.", "Bullying", "Schooling and education, whether we coped or not and achieved or not.", "Coordination and team sports.", "What peoples' special interests were, might be interesting as girls and boys are supposedly different in their special interests. And were you ever able to share that interest with anyone?"")

4th April - 18th April: "Personal identity (including sexual identity)"

(comments leading up to that were: ""Our awareness of our difference from others, the specific differences we were aware of as well as general feelings about it, how we processed that and made sense of it.", " "Gender rules" and how much of androgyny with people with Asperger's might be hormonal, and how much might simply be choice of non-conformity.", "Why people on the spectrum are less likely to conform to "norms" of any kind.", "A broader discussion of how often with young girls it is "not understanding" of gender roles, and how much is conscious choice.", "Development of a unique self - identity.", "The effect of being autistic on self-identity", "Puberty, emerging sexuality and sexual identity.", "Gender bending")

23rd April - 7th May: "Misdiagnosis and co-morbidities".

(comments leading up to that were: "" Misdiagnosis", "Co-morbidities (I have CAPD, prosopagnosia, and dyspraxia, for example).", "Co- morbidities, both psychological and medical.", "At what kind of age group might we have benefited by knowing about Asperger's."")

7th May - 14th May: "Emotions, emotional regulation and sensory issues"

(comments leading up to that were: ""Emotional regulation (or lack of).", " Emotions", " Mental health", "Sensory issues leading to anxiety", "Childhood and stims", "Suicide", "Suicidal depression", "Blame/shame the victim", "Selective mutism", "Anxiety", "Fears as a child which ties into the anxiety.", "Anxiety as a "normal" state on the spectrum (i.e. not pathological)", "The

experience of being overwhelmed - how did you experience it, were you able to explain what was going on or anticipate it?", "Communication and ability to communicate needs. That ties into emotional regulation and sensory overload.")

14th May - 28th May: "Personal safety and relationships with others"

(comments leading up to that were: ""Personal safety"., "The topic of personal safety is MOST important. The incidence of abuse on many different levels is likely to be prevalent.", "Friendships and the form they took", " Friendships", "Expectations from adults (including in the eras prior to Asperger's being recognised) - including mistaken ideas as to \*why\* the child behaves as he/she does!"")

Those are some of the subjects suggested so far. Feel free to comment on these or add even more to each topic!

YOUR LIKES MATTER! If you don't feel comfortable posting (which of course you are all encouraged to do) please connect at the group from time to time to "like" other people's comments, because I am trying to get as much participation from you as possible! Thank you! 😊

The comments mentioned above were subjects the participants suggested as areas they would like to discuss during this project.

## **LAY SUMMARY**

**Background:** This paper is trying to look at a new part of autism research. It reports on what autistic adults who were raised as girls say about their feelings in relation to their gender – whether they feel more like typical women, more like typical men, or feel differently to both.

**Method:** The research used online discussion groups and forty-three individuals who had been raised as girls chose to join the group and be part of the research. Participants from eight countries decided what they would talk about. This means that they chose the topic of gender identity as one that was important to them.

**Results:** Most said that they did not feel like they were similar to typical women and they gave different reasons for this. Some thought it was because they were autistic and some thought it was to do with people around them putting pressure on them to be more 'girly'. Participants often said they had been tomboys or wanted to be a boy growing up and their personal interests were very important to them.

**Conclusions:** The discussion looks at how autistic people are sometimes forced to act in certain ways in order to fit in, and how this can make them feel confused and depressed. The

research design was led by the participants and this meant that a group who have rarely been asked their opinion were able to have a say. Because the research was all online, the participant group could be larger than usual and came from all over the world. This paper shows that it is important to understand a person's environment, in order to really understand how autism affects them. It also shows that autistic people can give important information that helps others understand them better, and the only way to get this type of information is to ask autistic people.

## TABLES

Table 1: Key Data Tasks and Participant/Researcher Roles

Data task	Participant	First author
Stage 1: Unstructured discussion on potential topics	Contributes ideas	Themes ideas into 5 most popular topics
Stage 2: 5 unstructured discussion topics, staggered over a 3 month period	Contributes to any or all topics by posting or 'liking' posts	Analyses data into themes and sends out to participants for comment
Stage 3: Feedback on final dissertation	Provides commentary on final dissertation	Incorporates commentary into the final dissertation

Table 2: Participants' responses regarding gender identity

Themes	Mentioned by participants: (comments or specific likes)
Not relating to typical presentation/activities of the female gender	21



Fluid sense of gender/gender queer/ identifying with both genders	9
Tomboy	8
Sense of identity revolving around interests or company	8
Enjoying both female and male activities	7
Wanting to be a boy growing up	7
Not identifying with either gender	7
Feeling more like a boy than a girl/Transgender	1